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Unspoken pain: its assessment in persons with aphasia

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Chapter 6

**User-friendliness of
the Pain Assessment
in Impaired Cognition
(PAIC15) in persons with
aphasia: a pilot study**

Keywords:

- ~ pain;
- ~ pain observation;
- ~ aphasia;
- ~ user-friendliness;
- ~ PAIC15;
- ~ user-friendliness

Background: Persons with aphasia have difficulties communicating pain symptoms.

Methods: Thirteen observers performed multiple observations using the Pain Assessment in Impaired Cognition (PAIC15) scale for persons with aphasia during rest and transfer in persons with aphasia. This pilot study examined the user-friendliness of PAIC15 and preference for type of self-report pain scales with a questionnaire.

Results: The PAIC15 was considered user-friendly for persons with aphasia: items were clear and not difficult to score. When self-report is possible, the combined scale with verbal, visual, and numerical elements is preferred for persons with aphasia.

Conclusion: PAIC15 is a helpful instrument to aid clinical judgement and to screen for the presence of pain in persons with aphasia. There were mixed opinions, but most observers preferred to use the combined self-report scale for persons with aphasia.

Plain language summary

The Pain Assessment in Impaired Cognition (PAIC15) is an observation instrument that can be used to screen for pain in persons who are not able to express themselves. The pilot study investigated if the PAIC15 is user-friendly when applied to persons with aphasia (i.e., a language disorder caused by brain damage). A questionnaire about the user-friendliness was filled in by 13 persons who used the PAIC15 to observe persons with aphasia during rest and during transfer. The PAIC15 was considered user-friendly for persons with aphasia by all observers. The items of the PAIC15 were clear and not difficult to score, prompted observers to pay attention to non-verbal signals in persons unable to express themselves, and facilitated clinical judgement. Compared to self-report pain scales which cannot be completed due to aphasia, the PAIC15 observation instrument is easy to use to screen for the presence of pain in persons with aphasia.

Article Highlights

- PAIC15 was considered user-friendly when used to observe persons with aphasia.
- PAIC15 prompted observers to pay attention to non-verbal signals in persons unable to express themselves.
- PAIC15 facilitated clinical judgement of healthcare professionals when screening for pain in persons with aphasia.
- Observers preferred the use of a combined self-report pain scale for persons with aphasia who were still able to self-report pain.

Introduction

Self-report pain scales are the golden standard to assess pain in persons with aphasia. Examples are the Faces Pain Scale (FPS) ¹, Numerical Rating Scale (NRS) ² and Visual Analog Scale (VAS) ³. However, it is not clear which self-report scale is preferred for use in persons with aphasia ⁴. Also, for patients with severe aphasia, self-report is often not possible ⁵. Cognitive and communication impairments complicate identifying and treating pain in persons with aphasia, resulting in suboptimal pain management and therefore a negative impact on quality of life and care ^{6, 7}. As an alternative for self-reporting, an observational instrument could be used to screen for the presence of pain.

The psychometric properties of the pain observation instruments Pain Assessment Checklist for Seniors with Limited Ability to Communicate – Dutch version (PACSLAC-D) ⁸ and the Pain Assessment in Impaired Cognition (PAIC15) have been examined in persons with cognitive impairment, indicating their potential usefulness for clinical practice ^{9, 10}. The PAIC15 was developed by selecting items from existing observational scales and critically re-assessing their suitability to detect pain in patients with impaired cognition, especially dementia, using the combined expertise of clinicians and researchers ^{11, 12}. The PAIC15 has shown satisfactory psychometric qualities in several types of diseases with impaired cognition, such as Huntington's or Korsakov's disease ¹²⁻¹⁴.

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The PAIC15 comprises three categories with 5 items each. The categories are facial expressions (frowning, narrowing eyes, raising upper lip, opening mouth, and looking tense), body movements (freezing, guarding, resisting care, rubbing, and restlessness) and vocalizations (using pain-related words, shouting, groaning, mumbling, and complaining). The presence of the fifteen items is scored from 0 (not at all) to 3 (great degree) or as 'not scorable'. A sum-score can be calculated, ranging from 0 to 45, with higher scores indicating a greater degree of observed pain. For screening in practice, scores of ≥ 3 are indicative of pain ¹⁵.

Essentially, the observational instrument also needs to be user-friendly to ensure its application in clinical practice. So far, the user-friendliness of the PAIC15 has not been examined. The aim of this pilot study is to assess the user-friendliness of the PAIC15 to observe persons with aphasia. User-friendliness refers to the ease with which the PAIC15 can be used by healthcare professionals to achieve the intended goal of pain assessment in persons with aphasia. A secondary aim is to examine which of the four used self-report pain scales (i.e., VAS, NRS, FPS, and combined scale) the observers thought most user-friendly for persons with aphasia who are able to self-report.

Methods

This pilot study used a questionnaire among observers who used the PAIC15 in a study examining the reliability and validity of the PAIC15 in patients with aphasia ¹⁶. Comparison with self-report pain scales was chosen to assess whether the results of the PAIC15 and the measured construct match. The observations for the psychometric study were performed between

April 2019 and September 2021. The data of the current study were collected between March and September 2021.

The convenience sample of observers consisted of members recruited from the 19 participating care organizations via their speech and language therapist, and master-students (psychology and medicine) ¹⁶. Observers received information about the study and were asked to contact researchers if they were willing to participate. The observers must have performed observations with the PAIC15 in long-term care with persons with aphasia.

The current pilot study was assessed by the Medical Ethics Review Committee Leiden-The Hague-Delft (protocol number: P18.230, March 7, 2019) and declared exempt from the Medical Research Involving Human Subjects Act. The observers received a small gift for conducting the observations for the PAIC15 study.

— Instruments

The questionnaire to assess user-friendliness consisted of three parts. In the first part, observers were asked to provide demographic characteristics (i.e., age, gender, profession, years of experience with patients with aphasia). In the second part, observers were asked to rank the self-report pain scales Faces Pain Scale (FPS) ¹, Numerical Rating Scale (NRS) ² and Visual Analog Scale (VAS) ³, and combined scale from most to least useable for persons with aphasia. They clarified and discussed their ranking in an open-ended item.

The VAS offers a 10-centimetre line with ‘no pain’ at one end and ‘unbearable pain’ at the other end. The NRS consists of a line with numbers from 0 ‘no pain’ to 10 ‘worst pain imaginable’. The FPS shows six coloured vertically placed cartoon-faces ranging from no pain (dark green smiling face) to worst pain (dark red sad face). The combined scale combines these three self-report pain scales into one scale using the numbers zero to ten, coloured smileys, and written expressions of pain displayed along a vertical line. This combined self-report pain scale ensures a reinforced information display for clarification and support communication with persons with language problems ¹⁷. For each self-report scale, the person was asked to indicate the intensity of experienced pain on the line.

In the last part of the questionnaire, observers were asked about their experience with and the user-friendliness of the PAIC15 in persons with aphasia using nine items. The items about user-friendliness were ‘Do you find the PAIC15 useful for persons with aphasia?’(yes/no), ‘In general, could all items of the PAIC15 of the category facial expressions / body movements / vocalizations be scored?’ (yes/no/variable), ‘What is your general experience of observing persons with aphasia with the PAIC15?’ (0-10, with 0=very bad – 10=very good), ‘To what extent was the PAIC15 difficult or easy to use in persons with aphasia?’(4-point Likert scale from ‘Not difficult at all, almost no item was difficult’ ¹ to ‘Very difficult, almost all items were difficult’ ⁴), and ‘To what extent do you consider the PAIC15 suitable for use in clinical practice for screening pain in persons with aphasia’(0-10, with 0=very unsuitable – 10=very suitable). After each item, observers had the opportunity to clarify their answer in an open text field.

~ Procedure

All observers completed the PAIC15 eLearning (www.paic15.com/) and a 1-hour training provided by the primary researcher and trained and experienced speech and language therapist (NJdV) about the aim and procedure of the psychometric study, including practical tips and recommendations for conducting observations. Before conducting the observations, observers first checked whether persons with aphasia were able to self-report ¹⁶. If their language comprehension was deemed sufficient, the persons with aphasia were asked to complete the self-report pain scales. Next, the persons with aphasia were observed using the PAIC15 for a minimum of five minutes and a maximum of ten minutes during rest (e.g., participant could be lying in bed or sitting in a chair or wheelchair) and transfer (e.g., physical moves from bed to chair or wheelchair, repositioning in bed, a short walk, or receiving physiotherapy). Afterwards, if possible, the participant completed the four self-report pain scales. The order of the first three self-report pain scales was randomized, while the final self-report scale was always the combined scale. The observers did not know the persons they observed. After completing the observations for the psychometric study, observers received the user-friendliness questionnaire on paper. After two weeks, a reminder was sent to complete the questionnaire. The completed paper questionnaires were entered into Castor Electronic Data Capture (EDC), Castor Academy, version 2022.2.1.

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~ Analysis

Descriptive statistics were used to assess user-friendliness. All analyses were carried out with SPSS, IBM SPSS Statistics 25.0 for Windows, 2017 (SPSS, Chicago, IL, USA).

Results

All 13 observers were female with a mean age of 34 years (SD 13, range 22 – 53, median 28, IQR 24 – 51). Their experience with persons with aphasia ranged from 0 to 28 years (median 5, IQR 0 - 15). The observers were speech and language therapists (n=5), nurses (n=2) and master-students (n=6). Six observers used the PAIC15 between 0-5 times, three between 5-10 times, and three more than 10 times for persons with aphasia during this study (data of one observer missing).

~ User-friendliness

The general experience with the PAIC15 for persons with aphasia was rated 8.0 out 10 (SD=0.7, range 7 – 9, median 8.0, IQR 8 – 8). The PAIC15 was considered user-friendly for persons with aphasia by all observers (100% Yes; n=12, 1 missing); *“For the self-report pain scales, some communication was necessary to explain how it worked. When observing persons with communication problems, it was possible to see differences between persons. A person possibly experiencing pain could not indicate this on the self-report scales, but it could be clearly observed with the PAIC15.”* – Student ID18. Other elaborations on user-friendliness included the items

being clear and not difficult to score, they prompted observers to pay attention to non-verbal signals in persons unable to express themselves and facilitated clinical judgement. *“It ensures that you do not fill in the blanks for persons but keep looking objectively.”* – Speech and language therapist ID5.

The PAIC15 was assessed as not being difficult to use for persons with aphasia by 4 of the 13 observers (31%), while the other 9 observers (69%) considered it just a little difficult. None found the PAIC15 somewhat or very difficult to use for persons with aphasia. The numbers of items to observe in combination with quick changes that may occur in facial expressions, vocalizations and body movements in persons, made observations challenging at times. Table 1 provides an overview of all items the observers could score under facial expressions, body movements, and vocalizations, including the explanations that were reported. One observer indicated that more experience with the PAIC15 made it easier to distinguish the vocalization items. Some observers mentioned that a few items did not occur during their observations, especially during rest (for example ‘resisting care’ as no care was then given, or no staff were present).

Table 1: Observed items of the PAIC15 for facial expressions, body movements, and vocalizations in persons with aphasia

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Could all items of the PAIC15 of the following category be completed:	Yes (n)	No (n)	Explanation by observers when selected ‘No’ or ‘Variable’ (n)
Facial expressions	8	0	<ul style="list-style-type: none"> ↪ ‘Opening mouth’ can also be part of aging or other complaints (2/5) ↪ Did not always see the face clearly or difficult to score due to (hemi-)facial paralysis (1/5) ↪ Easy to miss certain facial expression when expressions change quickly (1/5) ↪ ‘Raising upper lip’ difficult to score in combination with ‘opening mouth’ (1/5)
Body movements	7	3	<ul style="list-style-type: none"> ↪ ‘Resisting care’ was not observed during rest (5/6) ↪ Some persons hold onto a body part, because they have learned to do so [by staff] to improve ADL^a care, making it difficult to distinguish it from ‘guarding’ (1/6)
Vocalizations	9	0	<ul style="list-style-type: none"> ↪ Some persons were not able to or it was unclear whether they could make vocalizations, so this section could then not be scored (2/4) ↪ Difficult to differentiate between the items (1/4) ↪ ‘Shouting’ and ‘using pain-related words’ did not occur during observations (1/4)

a = ADL= Activities of Daily Living

The PAIC15 useability for persons with aphasia in clinical practice was rated 8.1 out of 10 by the observers (SD=0.9, range 6 – 10, median 8.0, IQR 8 – 8). They regarded the PAIC15 as user-friendly, a helpful addition to clinical judgement, and a valuable tool to screen for the presence of pain in persons with aphasia: *“The PAIC15 is easy to use and can be filled in quickly. A brief moment of observation can give an indication of whether pain may be present, so that it can be further investigated and treated more quickly. Pain complaints that the person with aphasia has but is unable to express can still be noticed this way.”* – Student ID13.

Two observers mentioned that successful application in practice would depend on the quality of the implementation and the support base within the organization. *“A manual must be made available before implementation. Especially because physicians may prescribe additional or less medication.”* – Speech and language therapist ID5. Another observer mentioned that: *“The tricky part is that you have to observe consciously because otherwise you miss things, and this takes more time than the self-report scales. I think in busy clinical practice, the nurses can easily forget to really think about this and not take their time, and they may fill the PAIC15 based on what they noticed during daily care. They may, for example, not pay specific attention to facial expressions, and I think the PAIC15 then becomes less reliable.”* – Student ID19.

Preference of self-report pain scale

Table 2 presents the observers’ ranking of the four self-report pain scales for persons with aphasia who can self-report pain from most to least user-friendly for this population. Most (8 of 13) observers preferred to use the combined scale for persons with aphasia, as it was thought that the amount of information provided best facilitates self-report in persons with aphasia. *“Usually, I start with the combined scale, but sometimes I observe that the information seems to be too much and then I switch to the FPS. I use the VAS least with severe aphasia, I find it the most difficult to explain.”* – Speech and language therapist ID7. The VAS was preferred least (5 out of 13): *“The VAS is the vaguest and can be interpreted differently by everyone”* – Student ID13.

Table 2 Ranking of four self-report pain scales from most to least useful for persons with aphasia

Self-report scale	1 st preference (n)	2 nd preference (n)*	3 rd preference (n)*	4 th preference (n)
VAS	2	2	4	5
NRS	0	6	4	3
FPS	3	6	2	2
Combined scale	8	0	2	3

N=13 * one observer had no preference for NRS or FPS, giving them both the score ‘2nd preference’ and had no ‘3rd preference’. VAS= Visual Analog Scale, FPS= Faces Pain Scale, NRS= Numerical Rating Scale.

However, those who least preferred the combined scale mentioned that the scale was confusing due to all the information; “[combined scale] *too much noise*” – Speech and language therapist ID5. Interestingly, speech and language therapists either preferred the combined scale most or least for persons with aphasia. One speech and language therapist (ID4) suggested: “*Combined scale most useful [...] Depending on the language skills of the person, you can also cover parts if it is too confusing.*”

Discussion

This study examined the user-friendliness of the PAIC15 and observers’ preference for self-report scales for use in persons with aphasia. All observers found the PAIC15 user-friendly in persons with aphasia. Most observers preferred to use – when the person with aphasia was able to self-report pain – the combined self-report scale, although there were some mixed opinions in preferences.

Using the PAIC15 to assess pain in persons with aphasia forced observers to pay attention to non-verbal signals in persons who are not able to communicate their pain and facilitated clinical judgement about the presence of pain. Comparison of this finding with other studies on pain in persons with cognitive impairment confirms the recommendations of using an observational pain scale in persons who cannot complete a self-report pain scale^{18, 19}. Kaasalainen et al.²⁰ concluded that items of facial expression were observed more frequently among persons who were not able to verbally report their pain compared to persons who were. This suggests that observing facial expression and using an observational pain assessment instrument is paramount when assessing pain in persons with communication problems^{10, 21}. Nurses or healthcare professionals can miss facial or other behavioural items when they simultaneously support the person with aphasia during a transfer or activity. This was mentioned by the observers that made the PAIC15 a little difficult to use at times. To prevent this, it is recommended that someone else observes while the nurse or healthcare professional provides care or support during a transfer or activity¹⁰.

Additionally, the current study assessed which of the four used self-report pain scales (i.e., VAS, NRS, FPS, and combined scale) the observers thought most user-friendly for persons with aphasia who can self-report their pain. Although there were some differences in the ranking, most observers preferred to use the combined self-report pain scale for persons with aphasia, because the amount of information in this scale best facilitates self-reporting of pain in persons with aphasia. In line with our study, research on the use of self-report pain scales in persons with dementia found a significantly better comprehension of the Verbal Rating Scale²² and FPS, which provide more written and visual information than VAS²³. A self-report pain scale with more information may improve the likelihood that the person comprehends the request and can provide an answer. We recommend selecting a self-report scale that provides more information, both verbal and non-verbal, to use for persons with aphasia who are still able to self-report.

The observers followed the PAIC15 e-learning and received a training and instructions, before completing the observations for the psychometric study, to score only what they observe without interpretations. However, scoring of the PAIC15 items with the scores slight degree (1), moderate degree (2) or great degree (3) varied and resulted in discussion during consensus meetings²⁴. The recurring question was when to score the item 1, 2 or 3. This became more apparent as the observers gained more experience with PAIC15. In addition to the training, it is recommended to check and practice observations using the PAIC15 in persons with aphasia. Recently, the e-learning of PAIC15 has been updated with specific instructions regarding the assessment of the 15 items and the differentiation of the 3 proposed scoring options, based on the current as well as other recent studies. Not all items of PAIC15 could be observed during rest. Therefore, observing persons with aphasia using PAIC15 is most appropriate during a transfer or activity to observe pain caused by mobility. However, repetition of e-learning or practice sessions are recommended to increase the competencies and skills of nurses and healthcare professionals and the quality of pain observation assessment using PAIC15.

Although the small all female sample size limits generalizability, the results are still relevant as this is the first pilot study to examine the user-friendliness of self-report scales and an observation pain scale in persons with aphasia. The strength of this research lies in the deployment of various observers, the application of an extensive pain panel using four self-report pain scales and the use of pain observation instrument PAIC15. Future studies should also collect information on the preference of the persons with aphasia regarding the self-report pain scales. More research on the user-friendliness of PAIC15 using a larger and more diverse sample is needed to replicate the findings. In addition, it is recommended to conduct further research in an international context.

Conclusion

The PAIC15 can be regarded as user-friendly, a helpful addition to facilitate clinical judgement, and a valuable tool to screen for the presence of pain in persons with aphasia. Most observers preferred to use the combined self-report scale for persons with aphasia because of the information this scale provides to facilitate self-report in persons with aphasia. The use of the PAIC15 can be recommended as an alternative to improve pain assessment and management in persons with aphasia who are not able to communicate their pain.

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Ethical disclosure

The study was declared exempt from the Medical Research Involving Human Subjects Act by the Medical Ethics Review Committee Leiden-The Hague-Delft (protocol number: P18.230, March 7, 2019).

Authors' contributions

All authors have had substantial contributions to the design of the study. NJdV collected the data. NJdV and HJAS analyzed and interpreted the data and drafted the manuscript. JTvdS and WA reviewed the manuscript critically. All authors gave final approval of the manuscript to be published.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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Data availability statement

Data are available from the corresponding author upon request up to 5 years after publication.

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References annotations

Papers of special note have been highlighted as either of interest (*) or of considerable interest (**) to readers.

* de Vries, N. J., Sloot, P. H., & Achterberg, W. P. (2016). Pain and pain assessment in stroke patients with aphasia: a systematic review. *Aphasiology*, 31(6), 703-719.

This study reports the prevalence and incidence of pain in persons with aphasia after stroke, presents an overview of which pain assessment instruments are used, and examines whether they are feasible, valid and reliable.

* van Dalen-Kok, A. H., Achterberg, W. P., Rijkmans, W. E., Tukker-van Vuuren, S. A., Delwel, S., de Vet, H. C., Lobbezoo, F., & de Waal, M. W. (2018). Pain Assessment in Impaired Cognition (PAIC): content validity of the Dutch version of a new and universal tool to measure pain in dementia. *Clin Interv Aging*, 13, 25-34.

This article describes the translation of the PAIC into Dutch and, determines whether the PAIC items are indicative of pain and whether items are specific for pain or other disorders, and quantifies content validity.

** de Vries, N. J., Smaling, H. J. A., van der Steen, J. T., & Achterberg, W. P. (2024). Validity and reliability of the Pain Assessment in Impaired Cognition 15 (PAIC15) observation scale in persons with aphasia. *BMC Neurol.*

This validity and reliability study of PAIC15 shows mixed but promising validity results and good reliability indicating presence of pain related behaviours. Also, authors concluded PAIC15 can be of additional value in the assessment of pain in persons with aphasia when self-report is not possible.

** Hadjistavropoulos, T., Herr, K., Turk, D. C., Fine, P. G., Dworkin, R. H., Helme, R., Jackson, K., Parmelee, P. A., Rudy, T. E., Lynn Beattie, B., Chibnall, J. T., Craig, K. D., Ferrell, B., Ferrell, B., Fillingim, R. B., Gagliese, L., Gallagher, R., Gibson, S. J., Harrison, E. L., Williams, J. (2007). An interdisciplinary expert consensus statement on assessment of pain in older persons. *Clinical Journal of Pain, 23*(1 Suppl), S1-43.

This paper represents an expert-based consensus statement on pain assessment among older adults. It is intended to provide recommendations that will be useful for both researchers and clinicians.

** Kaasalainen, S., Akhtar-Danesh, N., Hadjistavropoulos, T., Zwakhalen, S., & Verreault, R. (2013). A Comparison Between Behavioral and Verbal Report Pain Assessment Tools for Use with Residents in Long Term Care. *Pain Management Nursing, 14*(4), E106-E114.

This study evaluates four pain assessment tools for use with long-term care residents who were able to verbally report their pain and those who were not, and to assess whether pain behaviours displayed vary as a function of ability to self-report pain.

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